PERSPECTIVE

Congenital Heart Disease: Would It Be the Key Driver of Infant Survival During *Amrit Kaal* (2022-2047)?

Arun K Baranwal,[1] Shankar Prinja,[2] Navpreet Kaur[1]

[1]Department of Pediarics, Advanced Pediatrics Center, Postgraduate Institute of Medical Education and Research, Chandigarh. [2]Department of Community Medicine and School of Public Health, Postgraduate Institute of Medical Education and Research, Chandigarh.

Correspondence to: *Prof Arun Kumar Baranwal, HDF Unit, Department of Pediatrics, Advanced Pediatrics Center, PGIMER, Chandigarh 160 012. baranwal1970@gmail.com*

Post-independence, we made significant strides in childhood survival. However, there is an abysmal improvement in survival due to birth defects. Globally, India contributes the largest proportion of under-5 deaths, overall as well as due to birth defects. Congenital heart disease (CHD) is the single most common cause of birth-defect related deaths, and is the 7th most common cause of infant deaths. Scarcity of pediatric cardiac care professionals and pediatric cardiac centers has led to a huge demand-supply gap. Understanding the burden of CHD and taking imperative steps at primary, secondary and tertiary levels are essential during *Amrit Kaal* (2022-2047). Coverage of management of CHD under *Janani Shishu Suraksha Karyakram, Rashtriya Bal Suraksha Karyakram* and *Ayushman Bharat* programs offers a huge promise, as shown by the experience from *Hridayam* program in Kerala.

Keywords: *Birth defects, Infant mortality, Neonatal mortality, Under-5 deaths,*

Despite significant reduction in child mortality, India, a country with low-middle socio-demographic index (SDI), contributes the largest proportion of under-5 deaths to the world statistics [1]. During 1990-2017, contribution of birth defects to child mortality has increased, with reducing neonatal mortality rate (NMR) and under-five mortality rate (U5MR) [1,2]. We also contribute maximum to the global under-5 deaths attributable to birth defects [2]. Congenital heart diseases (CHD) contribute the most to birth defects (28%), and the single most common cause of deaths due to them [3,4]. Here, we discuss the significance if CHDs with respect to child mortality, our preparedness, and the way forward to deal with the situation during the 'Amrit Kaal' of our independence (2022-2047).

CONGENITAL HEART DISEASE AND CHILD MORTALITY

During the last three decades, child survival improved significantly due to improvement in antenatal and neonatal care, control of vaccine-preventable diseases, acute respiratory tract infections and diarrhea-dehydration, and nutritional programs. During 1990-2019, the NMR, infant mortality rate (IMR) and U5MR reduced significantly The data from the Sample Registration System (SRS) revealed birth defects moving up from the eighth to the fifth most common cause of infant deaths during the 12-years period (2004-06 vs 2015-17) [5,6].

General improvement in childhood survival during 1990-2017 increased the proportional contribution of birth-defects to U5MR [2]. Concurrently, improving diagnostics and increasing awareness led to a steady rise in the reported prevalence of CHD [7,8]. The two together moved CHD up from 8th to 7th most common cause of infant mortality [9]. With birth prevalence of CHD being 0.9% (range, 0.8-1.2%), estimated annual birth prevalence (EABP) in India is likely to be upwards of 2,40,000 [8]. EABP of CHD in different regions are as follows– 84,000 in Northern region (Jammu-Kashmir, Laddhakh, Punjab, Himachal Pradesh, Uttarakhand, Punjab, Haryana, Chandigarh), 52,000 in Eastern region (Bihar, Jharkhand, Odisha, West Bengal), 38,000 in Southern region (Telangana, Andhra Pradesh, Tamil Nadu, Karnataka, Kerala), 29,000 in Western region (Maharashtra, Gujrat), 23,000 in Central region (Madhya Pradesh, Uttar Pradesh, Chhatisgarh, Rajasthan) and 12,500 in North-eastern region (Assam, Sikkim, Meghalaya, Mizoram, Nagaland, Manipur, Arunachal Pradesh, Tripura) [8]. About 25% of these babies have critical CHD (i.e., requiring interventions in the first year of life). Many of these babies mimic sepsis and/or respiratory diseases during neonatal period, or get complicated with one.

For the lack of timely surgery, children with CHD consume healthcare resources unproductively for repeated hospitalizations for congestive heart failure, recurrent pneumonia, cardiovascular complications,

malnutrition and its associated problems. With passage of time, surgical outcome would be compromised in many, while many children would become inoperable. Thus, CHD is also an important cause of mortality and morbidity during later childhood as well. In fact, birth defects (of which CHD constitute the largest proportion) are estimated to contribute 8% of under-5 deaths in India [1]. Contribution is likely to be more in states with U5MR<25, e.g., Kerala, Tamil Nadu, Maharashtra, Delhi, Manipur and Nagaland. The same is likely to happen in most of other states as they are projected to achieve U5MR<25 by the year 2030, barring Uttar Pradesh, Madhya Pradesh, Chhatisgarh, Odisha, Rajasthan, Assam and Mizoram [1]. Another analysis revealed birth-defects to be the third leading cause of early neonatal mortality in 17 states [2]. With persistently improving SDI, awareness, institutional deliveries, neonatal, infant and under-5 survival, and lack of healthcare infrastructure to manage CHD in majority of states, a fairly constant birth prevalence of CHD would create a case of 'perceptual explosion' during the *Amrit Kaal*.

CURRENT STATUS

Care of Children With CHD

Level of care available for children with CHD varies significantly between high income countries (HICs) and low- and middle- income countries (LMICs). In HICs, the vast majority reach adulthood owing to breakthroughs in diagnosis and management. This; however, is not the case in LMICs. One fully equipped cardiac centre is estimated to serve a population of 1,20,000 in North America, while the same serves a population of 16 million in Asia. Similarly, one cardiac surgeon serves a population of 3.5 million in North America and Europe, while the figure in Asia is 1 per 25 million [8]. In India, a population of 141 crore is served by a handful of centers. We have very few trained professionals in various disciplines of pediatric cardiac sciences and intensive care. Scarcity of facilities in public sector hospitals is even more glaring. Even within the country, available pediatric cardiac facilities are unevenly distributed [8].

Until recently, children with CHD were being managed through out-of-pocket expenditure. Thus, the majority were unable to afford timely surgery. Implementation of flagship public healthcare schemes [e.g., Pradhan Mantri Jan Arogya Yojana (PM-JAY), Janani Shishu Suraksha Karyakaram (JSSK) and Rashtriya Bal Swasthya Karyakram (RBSK)] is likely to become a game-changer. Despite availability of funds through such schemes, proportion of children with CHDs getting operated differs substantially across different regions of the country — Central region (7.6%), Eastern region (12%), Northern region (17%), Western region (28%), Southern region (74%), while none get operated in the North-Eastern region [8,10]. Capacity, both infrastructure and human resource, is the prime limitation for the observed demand-supply gap, especially in northern and eastern regions.

The Hridyam Program

IMR in Kerala was 16/1000 livebirths in 1991, and it stagnated around 10-12 for about a decade (2007-2017), despite reduction in neonatal and infant deaths with improvement in perinatal care, infectious diseases and malnutrition— the so-called 'low-lying fruits.' Birth-defects (of which CHD has the largest share) were found to be major contributor to infant death, and the second most common cause of under-5 deaths [2,11]. A plan of 'paediatric cardiac care continuum' was worked out to address the issue of CHD, especially the critical ones. It was implemented in August 2017 as '*Hridyam'* program in public-private partnership. Children (aged 0-18 years) with suspected CHD were registered to develop a life-time pathway instead of just providing one-time surgery. Program created a state-wide network connecting primary health centres to tertiary hospitals for timely and optimal management [11]. It led to fall in all-cause IMR to 6/1000 livebirths by the year 2019 (**Fig. 1).** Jammu-Kashmir, Punjab, Himachal Pradesh, Delhi, West Bengal, Maharashtra, Goa, Tamil Nadu and all Union Territories have already achieved an IMR of 20 or lesser, and more states are expected to join the league soon [1,12]. The CHD program may perceived to be expensive, cumbersome and unyielding, experience and evidence from the '*Hridayam'* program; however, suggest this to be the only way to reduce IMR further in these states.

THE WAY FORWARD

The Government of India is committed to achieve 'single digit' NMR by 2030 and U5MR of 23 by 2025 [13,14]. Stagnating contribution of neonatal deaths to under-5 deaths (i.e., ~55%) across states irrespective of their U5MR and SDI [1] suggests the need to shift on to the next paradigm of interventions. Birth-defect surveillance and management program is likely to reduce U5MR further, especially in states with U5MR<25 [2]. Diagnosis and management of CHD would be the most important aspect of this program.

Continuum of Care Through *Ayushman Bharat*

Experience from countries with high SDI revealed that identification of newborns with CHD before discharge from hospital, excellence in emergency care, and developments in pre-operative and post-operative intensive care, cardiopulmonary bypass and surgical techniques have dramatically improved survival of children with CHD [15].

Hridayam program provided a made-in-India model of community-based pediatric cardiac care continuum (beginning from the antenatal period to the postnatal evaluation, cardiac surgery and long term follow up), which may be replicated in other parts of the country. The experience gained may inform a national policy for children with CHD, which may work to develop a similar approach integrating JSSK and RBSK with PM-JAY. As part of comprehensive primary health care, obstetricians and sonographers at Health and Well-being Centers (HWCs) and district hospitals may be trained to detect CHD during antenatal period. Inclusion of essential physical cardiac examination and pre-discharge screening by pulse oximetry in the existing neonatal protocols would help to detect CHD before discharge. Healthcare providers may be trained to identify survivors of neglected CHD presenting to healthcare facilities or detected through school health programs. Suspicion of CHD would prompt timely referral and transport of in utero baby, neonate or older child to a designated tertiary care centre for detail assessment. Children with CHD thus identified may receive secondary and tertiary healthcare under public-funded schemes. Integration of HWCs with secondary and tertiary care centers may be enabled through care pathway linkages and information technology by creation of Ayushman Bharat Health Account (ABHA) ID, which would create a longitudinal health record for babies with CHD. Recently, follow up packages has been added under PM-JAY to provide continuous support even after discharge from hospital. National Health Authority introduced a digital payment voucher, e-RUPI to ensure uninterrupted access to diagnostics and therapeutics from providers of patients' choice. These person- and purpose-specific payment vouchers means public subsidy is provided only to the needy and only for the intended purpose. Early diagnosis, prompt referral, provision of affordable treatment, combined with better post-operative home-based care, would be a game-changer in bringing down the attributable infant and child mortality.

Developing Pediatric Cardiac Care Services in the Public Sector

Establishing at least one premier Center of Excellence (CoE) in each region is an urgent need of the hour. Northern and eastern regions may be prioritised in view of wider demand-supply gap; the former has lower U5MR as well. These centers should have five essential, distinct and child-specific specialized clinical service verticals working in horizontal collaboration– Pediatric (diagnostic and interventional) Cardiology, Pediatric Cardiac Radio-imaging, Pediatric Cardiac Intensive Care (to provide specialized intensive care services before and after cardiological intervention and cardiac surgery), Pediatric Cardiac Surgery and Pediatric Cardiac Anaesthesia. Cardio-pulmonary bypass, extracorporeal membrane oxygenation and pediatric cardiac critical care nursing services are essential component of the CHD program. Ancillary services should include Pediatric Cardiac Airway, Pediatric Cardiac Pulmonology and Cardiac Genetic services. Creating CoEs in the established institutes of national importance (INIs), as extension of their pediatric services, is likely to be logistically and financially prudent. These CoEs would act as apex institutions, and would provide training-learning opportunities, develop academic

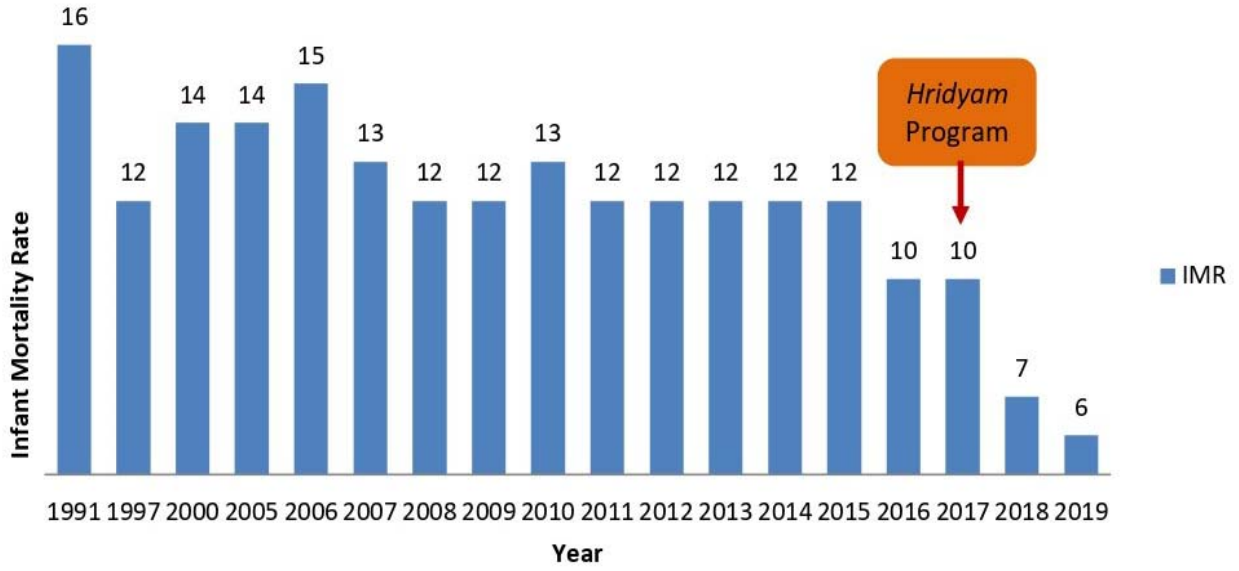

Fig. 1 Effect of Hridayam program on the stagnating infant mortality rate in Kerala (1991-2019).

programs, help capacity-building and stimulate country-specific research and innovations [8].

Strengthening behaviour change communication: Public awareness needs to be created about long-term survival of most of the CHD patients. It may improve health-seeking behavior within community. Emphasis on primary prevention by reducing consanguinity, immunization against rubella, reducing risk factors like smoking, alcohol intake during pregnancy, supplementing folic acid during first trimester, and optimal control of diabetes should also be on cards [16].

Human Resource Development

Management of CHD needs development of specialized professionals in various disciplines of pediatric cardiac sciences as mentioned above. At present, we only have a post-doctoral (DM) program in Pediatric (diagnostic and interventional) Cardiology, and that too only at All India Institute of Medical Sciences-Delhi and Postgraduate Institute of Medical Education & Research-Chandigarh. There are no post-doctoral programs in the other four essential disciplines. While establishing CoEs may be a long-term goal, post-doctoral programs need to be started immediately with horizontal integration of resources from Departments of Pediatrics, Cardiology, Cardiovascular Surgery, Radiodiagnosis and Anesthesia in the established INIs **(Table I)**. The National Medical Commission (NMC) and National Board for Examinations in Medical Sciences (NBEMS) may find inclusion of these academic programs in their bouquet of post-doctoral courses as visionary, and as need of country's near future. Training programs to create a pool of perfusionists, pediatric cardiac critical care nurses and other professionals required for in-hospital and out-of-hospital care of children with CHD may also be planned (**Table I)**. Initiation of pediatric cardiac services and training programs in various disciplines of pediatric cardiac sciences in the new generation of tertiary healthcare institutions of national importance (e.g., the new All India Institutes of Medical Sciences) and the autonomous tertiary healthcare institutions under various state governments would significantly improve the access across the country. They would also help create locally-relevant innovative approaches towards CHD program. These initiatives are likely to lead to development of a comprehensive and sustainable India-made ecosystem to effectively deal with the epidemiological transition during *Amrit Kaal* (2022-2047).

Deliverables

Improved childhood survival is likely to improve life expectancy at birth and thus our Human Development Index [1]. Creation of a large public-funded healthcare scheme would lead to new investments in healthcare, pharmaceutical, manufacturing and biomedical engineering sectors. A relatively stable birth prevalence of CHD, large population, huge demand-supply gap and locally relevant research/innovation would make the indigenously developed CHD program self-sustainable, scalable and replicable. Shift of care of CHD from currently dominant private corporate hospitals to the public healthcare delivery system is likely to benefit domestic industry, as has been seen in the vaccine sector [17,18]. An economically competitive CHD program could also foster medical tourism. All these would end up generating employment for unskilled, skilled and highly skilled personnel. In a nutshell, such a CHD program would fulfil objectives of Atmanirbhar Bharat Abhiyaan, Heal-in-India and Health-by-India programs, and would be an important component of roadmap to India@100.

CONCLUSIONS

With reducing child mortality, CHD is becoming a key driver of childhood survival. Multilateral collaboration between

Table I Proposed Training Programs in Various Disciplines of Pediatric Cardiac Sciences

Courses	*Disciplines*	*Eligibility*
DM	Pediatric Cardiology (Diagnostic and Interventional services)	MD/DNB (Pediatrics)
DM	Pediatric Cardiac Intensive Care (Intensive Care services before and after cardiological interventions and cardiac surgeries)	MD/DNB (Pediatrics/Anesthesia)
MCh	Pediatric Cardiac Surgery	MS/DNB (Surgery)
DM	Pediatric Cardiac Anesthesia	MD/DNB (Anesthesia)
DM	Pediatric Cardiac Radio-imaging	MD/DNB (Radiology/Radio-imaging)
B. Sc.	Perfusion Tecnology	I.Sc. (Biology)
Postgraduate fellowship	Pediatric Cardiac Nursing	M. Sc. (Pediatric Nursing)
Postgraduate fellowship	Pediatric Cardiac Critical Care Nursing	M. Sc. (Pediatric Nursing)
Postgraduate fellowship	Pediatric ECMO Nursing	M. Sc. (Pediatric Nursing)

policy makers, administrators, public health delivery system, private hospitals and pediatric cardiac professionals is urgently needed. It would help in developing and implementing pediatric cardiac care continuum across the country. At least one CoE per region needs to be established, prioritizing the under-served regions. Professional training programs may be initiated to create a sustainable ecosystem. An evidence-informed national policy may go a long way in managing the imminent epidemic of CHD, improving HDI ranking, and generating jobs in the run up to the centennial celebrations of our independence in the year 2047.

Funding: None; *Competing interests*: None stated.

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